THE RIGHT TO END-OF-LIFE PALLIATIVE CARE
AND A DIGNIFIED DEATH

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1. The right to life and dignity in old age

The approach of death involves a number of activities, as different practicalities pertaining to the end of life have to be organized. It is essential for these activities—which are carried out by family members, caregivers and medical personnel, among others—to meet standards that ensure appropriate living conditions until such time as clinical and biological death supervenes.

Older persons are among the most vulnerable to death. Their position in the age structure of society becomes almost by default a predictor of their demise. This social construction of old age prompts a particular way of treating the elderly: “The social structures in which [older persons] are involved are oriented to the fact of their forthcoming death; their families have become increasingly independent of them; the scope of references to the ‘future’ has progressively narrowed; ‘dying’ is of considerably less consequence for others, e.g., it is not felt to be a matter which requires drastic revision of others’ life plans, as does the ‘fact’ that a young adult is dying” (Sudnow, 1967).

Older persons are sometimes treated like cadavers even when they are, clinically and biologically, still alive. This occurs especially in cases where they are dying or suffering from terminal illnesses, although they do not necessarily have to be in this predicament to receive degrading treatment. There is often a predisposition to treat older persons as if they were dying regardless of how serious or irreversible their condition actually is.

Thus, society turns predictions of their death into self-fulfilling prophecies. Older persons requiring emergency care often do not receive the same treatment as younger ones, they are not hospitalized along with other patients suffering from the same illnesses, they are kept on stretchers or sitting in corridors, they are physically restrained to prevent falls, they are denied the presence of a companion or they are prevented from moving about independently, among other things. Moreover, according to experts, this behaviour has become so accepted that even older persons view behaviour that does not respect their dignity as conventional. For the dignity of life to be preserved until death, it is vitally important to change this way of behaving and to honour people’s expectations of what the end of their lives should be like, with every effort made to fulfill older persons’ wishes and provide all the support a dignified end requires.

1 This document has been prepared by Sandra Huenchuan, CELADE-Population Division of UN-ECLAC.
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doctors uncomfortable at dealing with elderly patients’ anxieties about death may choose to give them false hopes and treatments that actually shorten lives instead of improving them (Gawande, 2014).

Paradoxically, humankind is still discussing what to do about ensuring a dignified death. There is a debate about what should be protected: the conditions of death or the ability to choose when to die.4

The boundary between these two options is clearer in Latin America and the Caribbean than in other regions. The Inter-American Convention on Protecting the Human Rights of Older Persons plainly identifies the conditions required to maintain dignity until death: “States Parties shall take steps to ensure that public and private institutions offer older persons access without discrimination to comprehensive care, including palliative care; avoid isolation; appropriately manage problems related to the fear of death of the terminally ill and pain; and prevent unnecessary suffering, and futile and useless procedures, in accordance with the right of older persons to express their informed consent” (article 6).

This instrument also defines palliative care as “[a]ctive, comprehensive, and interdisciplinary care and treatment of patients whose illness is not responding to curative treatment or who are suffering avoidable pain, in order to improve their quality of life until the last day of their lives. Central to palliative care is control of pain, of other symptoms, and of the social, psychological, and spiritual problems of the older person. It includes the patient, their environment, and their family. It affirms life and considers death a normal process, neither hastening nor delaying it.”

The ultimate goal of the Convention in this area is not a good death, but a good life until the end. It is for this reason that the instrument addresses palliative care so extensively, not only in article 6 on the right to life and dignity in old age, but in article 12 on the rights of older persons receiving long-term care, article 19 on the right to health and article 11 on the right to give free and informed consent on health matters.

In practice, some States have recognized a dignified death as a right whose protection requires timely and appropriate access to palliative care. In Costa Rica, for example, resolution 1915-92 of the Constitutional Chamber of the Supreme Court recognizes a right to die with dignity for those who are aware that they are dying and choose to do so painlessly. The resolution also recognizes the indisputable link between the right to health and the right to life: the fundamental purpose of the former is to give effect to the latter, given that this protects not only a person’s biological existence but all the other aspects deriving from it (Costa Rica, Sala Constitucional de la Corte Suprema de Justicia, 1993.).5

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4 In the United States, the State of Oregon allows its citizens to take self-administered lethal medications prescribed by a doctor under the Death with Dignity Act (DWDA) of 1997. The state of Washington passed a similar law in 2008, followed by Vermont in 2013. In Europe, the Swiss law permitting assisted suicide has been in force since 1942. In 2014, Belgium extended its 2002 euthanasia law to children. In the Netherlands, the law enacted in 2002 went a step further, allowing both assisted suicide and euthanasia in certain circumstances.

5 In the United States, the Supreme Court laid the foundations for a constitutional right to appropriate palliative care in its rulings on Washington v. Glucksberg and Vacco v. Quill (Quesada, 2008). In Europe, the European Court of Human Rights ruled in the case of Diane Pretty v. the United Kingdom that the response to euthanasia should be the promotion of palliative care (European Court of Human Rights, 2002).
2. The right to free and informed consent and advance directives

Some clarification is also needed regarding free and informed consent on health matters, as addressed in article 11 of the Inter-American Convention. The purpose of this was for older persons to be able to refuse health-care interventions that they did not desire or were forced to submit to in health-care institutions. In accordance with paragraph 2 of the International Covenant on Economic, Social and Cultural Rights and article 2 of the Universal Declaration of Human Rights, emphasis was placed on a favourable environment in which informed consent would be a priority and on guarantees of the greatest possible protection against stigmatization and discrimination.

One doubt that arises is whether article 11 favours euthanasia, specifically when it alludes to the following obligation: “States Parties shall also establish a procedure that enables older persons to express their wishes in advance with regard to health care interventions, including palliative care.”

Advance directives are instructions whereby a person makes known their wishes regarding certain medical interventions in the expectation that these will be respected and complied with by the doctor or medical team when that person is no longer in a position to express preferences (Montiel Llorente and García Alonso, 2007).

Article 11 of the Inter-American Convention must be interpreted in the light of article 6 on the right to life and dignity in old age. In this framework, advance directives are part of the kind of legislation that favours palliative and end-of-life care. The intention is not to prolong or shorten life but to respect the natural moment of death.

According to the Supreme Court of the United States, one of the advantages of advance directives is that they give people the comfort of knowing their preferences have been stated and are available to their families and doctors, and the peace of mind that comes from knowing they will be able to communicate with their families and doctors through a directive based on their personal philosophy, so that decisions can be taken without regret or remorse.

The United States has a living will registry that allows citizens to issue these directives. By contrast with the legal situation in some countries of the region, advance directives can be issued whether a person suffers from a terminal illness or not. This testimonial from the registry reveals how helpful such an instrument can be: “I am very glad I registered my advanced [sic] directive. As caregiver for my mother, my father, and my stepmother I cannot express the peace of mind that registering gives. My husband and

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6 During the ratification of the Inter-American Convention by Chile’s Parliament, for example, the Chamber of Deputies, prompted by a lawmaker, requested a review by various commissions to determine whether the provisions of the Convention could be interpreted as favourable to euthanasia or assisted suicide (see Boletín No. 10.777-01(C) of the Chamber of Deputies of Chile).

7 See the [Advance Directive Act for the Federal District](http://www.salud.cdmx.gob.mx/storage/app/media/Ley_Voluntad_Anticipada.pdf); current legislation in some Mexican states; and the advance directive decree in Uruguay ([online](http://www.msp.gub.uy/sites/default/files/archivos_adjuntos/DECRETO%20VOLUNTAD%20ANTICIPADA%20DEL%204%20DI%C2%AD%20DE%202013.pdf)).
daughter will never go through the stress of wondering if they are acting according to my wishes. It will be very clear for them. In a way, making my advanced directive is protecting my husband and daughter, even when I am seriously ill. When a loved one is seriously ill is the worst possible time to deal with the subtleties and ramifications of hospital and legal bureaucracies. This will free them from a lot of those worries” (name withheld, Kingston, Washington).

Despite the usefulness of advance directives, there is still much work to be done. There are conceptual misunderstandings that may limit the rights and freedoms of older persons, even in places where there is legislation. For example, the use of advance directives is still limited in Mexico City, with only 2,700 of these documents being registered between 2008 (when the relevant law was enacted) and 2013.

3. Palliative and other care for older persons

In 2011, over 29 million people worldwide are estimated to have died from diseases requiring palliative care, with 20.4 million of these needing it at the end of their lives. The great majority of adults needing end-of-life palliative care live in low- and very low-income countries, and the bulk of them (69%) are aged 60 or over (Connor and Sepúlveda, 2014).

In the United Kingdom, a country acknowledged to have made advances in the field, nurses and doctors who responded to a 2001 survey on end-of-life care for hospitalized patients gave it as their opinion that the care of dying older patients was characterized by a lack of emotional engagement with the patient and institutionalized non-disclosure of information about their deaths. Their responses indicated that although nurses provided individual care to dying patients, much of it was directed solely towards meeting their physical needs. The data show that death is sometimes badly managed in hospitals, with inadequate control of symptoms, insufficient support for patients and caregivers and little or no communication about prognoses or treatment (Costello, 2001). As a result, the pain associated with ageing has tended to become institutionalized and the perception that this is so has become a real obstacle to older persons receiving the care they need.

Palliative care also tends to be used as a substitute for curative care. Life-extending treatment is suspended by default when people are admitted to programmes of this type. In some cases, the older person’s presence is not even required for their admission into a palliative care programme to be evaluated, with decisions being taken on the basis of information supplied by third parties. In other cases, it is health-care professionals themselves who suggest palliative care for older people with terminal diseases without considering other forms of treatment.

It seems to be particularly hard where older persons are concerned to distinguish between curative treatment and care, which are usually interdependent. For example, a blood transfusion may be part of a treatment to restore health or to strengthen cancer patients so that they can receive palliative radiotherapy, and the same holds for dialysis. The line between the two types of treatment is ambiguous, and the reasons for their stark separation are of various kinds.

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One explanation concerns health-care professionals. As early as the seventeenth century, Francis Bacon wrote: “I esteem it the office of a physician not only to restore health, but to mitigate pain and dolors; and not only when such mitigation may conduce to recovery, but when it may serve to make a fair and easy passage” (cited in Abid, 2008).

Other reasons stem from the substantial gap between research and development investment in techniques for controlling symptoms and other aspects of palliative care and investment in life-prolonging techniques. There are also barriers within research and clinical systems that prevent many people from receiving effective palliative care where and when they need it (Foley and Gelband, 2001).

It would thus be a mistake to view the curative model and the palliative care model as the only two options available. The two models represent opposite ends of a spectrum in which limitless variations are possible, and leaping from one extreme to the other is seldom appropriate (Fox, 1997). Between the curative model and the palliative model, there is the person-centred approach. This means that when someone is suffering from a terminal illness, use must be made of the whole array of solutions offered by medicine to relieve pain and help the person live a full and satisfying life (Hadjistavropoulos and Hadjistavropoulos, 2008). According to WHO, this not only improves the quality of life of terminally ill patients, but reduces unnecessary hospitalizations and use of health services.

4. Palliative care as a State obligation

Access to palliative care is a legal obligation of States. Before the adoption of the Inter-American Convention on Protecting the Human Rights of Older Persons, this had already been recognized by the Committee on Economic, Social and Cultural Rights in general comment No. 14 (United Nations, 2000) and by the Committee on the Elimination of Discrimination against Women in general recommendation No. 27 (United Nations, 2010b). Consistently with this, the Special Rapporteur on torture established in a 2013 report that denying pain relief could constitute inhuman and degrading treatment, according to the definition of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (United Nations, 2013).

The Council of Europe has also included palliative care in recommendation CM/Rec(2014)2. Its explanatory report (CDDH-AGE, 2013) states that the legal basis for this inclusion is that human dignity must be respected at all stages of each individual’s life (including terminal illness and death) and that palliative care helps to preserve this dignity, providing an appropriate environment for such patients and helping them to deal with pain and other distressing symptoms. Hence, palliative care should be provided in all areas in response to the progressive needs of older persons. Within five years of the adoption of the recommendation:

- Member States should offer palliative care for older persons who suffer from a life-threatening or life-limiting illness to ensure their well-being and allow them to live and die with dignity.
- Any older person who is in need of palliative care should be entitled to access it without undue delay, in a setting which is consistent with his or her needs and preferences, including at home and in long-term care settings.
• Family members and friends should be encouraged to accompany older persons who are terminally ill or dying. They should receive professional support, for example by ambulatory palliative-care services.

• Health-care providers involved in palliative care should fully respect patients’ rights and comply with professional obligations and standards.

• Trained specialists in the field of palliative care should be available to lead education and research in the field. Programmes of palliative care education should be incorporated into the training of all health and social care workers concerned and cooperation of professionals in palliative care should be encouraged.

• Member States should ensure the adequate availability and accessibility of palliative care medicines.

• In the organization of their national palliative care systems, member States should take into account Recommendation Rec(2003)24 of the Committee of Ministers to member States on the organization of palliative care.

In relation to this last point, European countries have had a valuable directive on palliative care in place since 2003, but progress has been uneven. As this instrument is not binding, member States of the Council of Europe are not obliged to implement it fully.

Article 19 of the Inter-American Convention establishes the following State obligations regarding palliative care in addition to the guarantees mentioned previously:

• Promote and strengthen research and academic training for specialized health professionals in geriatrics, gerontology, and palliative care.

• Promote the necessary measures to ensure that palliative care services are available and accessible for older persons, as well as to support their families.

• Ensure that medicines recognized as essential by WHO, including controlled medicines needed for palliative care, are available and accessible for older persons.

Moreover, articles 6, 11 and 12 of the Convention call for non-discrimination and equality of access in the provision of palliative care.

In Mongolia (ranked 28), a notable development was the creation of the Mongolian Palliative Care Society (MPCS) in 2000. Before then, the country did not have palliative care services or programmes or a government policy in this area, and used just 1 kg of morphine per year. Beginning in 2003, palliative care...
care was incorporated into legislation and into the national cancer control programme. In 2013, Mongolia started including palliative care in the treatment of other chronic diseases and in home care.

In China (ranked 71), there is no national strategy or law guaranteeing access to palliative care. The national Ministry of Health has officially endorsed the establishment of palliative care departments in hospitals, but outside of the country’s 400 specialized cancer hospitals, only a few community health centres offer palliative care services.

In Spain (ranked 23), palliative care has evolved since the 2007 launch of a palliative care strategy by the national health-care system. In a country where health care falls under the authority of 17 regional health systems, this national approach has increased access to services. The launch of the national strategy has led to a 50% increase in palliative care facilities and unified regional systems.

The development of palliative care in South Africa can be attributed partly to government funding and partly to the participation of non-governmental organizations, notably the Hospice Palliative Care Association of South Africa. Religious institutions also have hospitals that offer palliative care. Moreover, South Africa has made progress in training and developing the skills of health-care professionals. The first master’s degree in palliative care catering to doctors, nurses and social workers was offered by the University of Cape Town.

According to research by Hospice UK, the number of people dying in hospital could be cut by 20% if care models were identified and their impact on families and communities assessed. The strategy of the United Kingdom, which tops the ranking, is based on reducing the number of people dying in hospitals every year and on providing patients with palliative home care packages that include nursing or a home carer, accompanied by the latest remote monitoring technology.

Taiwan Province of China (ranked 6) is a pioneer in technological advances, and these have a direct impact on the rights of patients and on the palliative care they receive. For example, all Taiwanese citizens have an insurance card with their medical information: older persons are encouraged to make specific end-of-life decisions about their wishes in the event that a resuscitation decision needs to be made, and this information is linked directly to their insurance card, so that it will come up when they register at any health-care facility.


5. Palliative care programmes for older persons in Latin America and the Caribbean

Most countries of the region do not meet the demand for palliative care and fail to recognize it as a discipline or to include it in public or private health-care systems. Fewer still have legislated for it, and funding and continuity have been impaired as a result.
The majority of national palliative care programmes in the region were created in the late 1990s, meaning the approach is fairly recent. There are isolated initiatives resulting from local efforts, but few countries have a national public policy guaranteeing access to palliative care.

In countries that do have national palliative care programmes, they are linked primarily to oncological diseases and can still be difficult to access for non-cancer patients, such as those living with HIV/AIDS or suffering from other chronic or terminal illnesses. The law does not require the provision of palliative care for these patients, and pain management with analgesics depends on whether doctors are authorized to prescribe opioids.

The lack of national policies has led to the emergence of private initiatives to provide care for the terminally ill, but at a very high cost, which debars low-income patients from access. There are also non-profit foundations that provide support and pain relief, although they lack duly accredited personnel. This situation threatens the sustainability of these activities, which are carried out mainly by volunteers and with resources from charitable and non-governmental organizations (NGOs).

A 2014 WHO study (Connor and Sepúlveda, 2014) presents an interesting classification of progress with palliative care around the world. In the region, most countries are in the early stages of developing this type of programme. For example, a large number of Caribbean countries (Antigua and Barbuda, Grenada, Saint Kitts and Nevis and Saint Vincent and the Grenadines) were classified at the lowest level, with no known palliative care activity (see table 1).

<table>
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<tr>
<th>Table 1</th>
<th>Latin America and the Caribbean: level of development of palliative care programmes, 2014</th>
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<tr>
<td>Level of development of palliative care programmes</td>
<td>Countries and territories</td>
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<tr>
<td>Group 1: No known activity</td>
<td>Anguilla, Antigua and Barbuda, Aruba, Falkland Islands (Malvinas), French Guiana, Grenada, Martinique, Montserrat, Netherlands Antilles, Saint Kitts and Nevis, Saint Vincent and the Grenadines, Turks and Caicos Islands, United States Virgin Islands.</td>
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<tr>
<td>Group 2: Capacity-building</td>
<td>Bahamas, British Virgin Islands, Dominica, Haiti, Honduras, Nicaragua, Plurinational State of Bolivia, Suriname.</td>
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<td>Group 3a: Isolated provision</td>
<td>Barbados, Belize, Bermuda, Bolivarian Republic of Venezuela, Brazil, Cayman Islands, Colombia, Cuba, Dominican Republic, Ecuador, El Salvador, Guadeloupe, Guatemala, Guyana, Jamaica, Panama, Paraguay, Peru, Mexico, Saint Lucia, Trinidad and Tobago.</td>
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<tr>
<td>Group 3b: Generalized provision</td>
<td>Argentina.</td>
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<td>Group 4a: Preliminary integration</td>
<td>Chile, Costa Rica, Puerto Rico, Uruguay.</td>
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<td>Group 4b: Advanced integration</td>
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At the second level are countries where some efforts have been made but there are as yet no established policies, such as Dominica, Haiti, Honduras, Nicaragua and the Plurinational State of Bolivia. In Honduras, for example, the available data show that there are no palliative care services or units at any of the three levels of care (Pastrana and others, 2012). There is no accredited training in palliative care, and nor is this included in the academic curriculum of the medical sciences faculty of the Universidad
Nacional Autónoma de Honduras. As a result, there are not known to be any specialists in this field. From a legal standpoint, there are still no laws or regulations on palliative care, which means that no government resources are allocated to it.\(^9\)

After this, WHO classifies Brazil, Colombia, the Dominican Republic, Ecuador, Mexico, Panama, Peru and Trinidad and Tobago, among others, as being at the stage where progress with palliative care programmes is hindered by lack of funding, medication is not widely available and coverage is limited.

In Peru, coverage is limited despite the existence of the Home Care Programme for Older Adults and Cancer Patients (ADAMO). Fewer than 2,000 older persons received home care in 2014. As regards training, there is no professional accreditation for doctors providing palliative care. The Peruvian Society of Palliative Care, a non-profit organization, is trying to fill the gaps by raising awareness and training medical professionals in pain management and palliative care.

In 1996, Brazil established the National Cancer Institute (INCA) in Rio de Janeiro. This cancer hospital, run by the Ministry of Health, offers the most comprehensive palliative care services in the country. Palliative care training is officially recognized as a subspecialty known officially as Área de Atuação em Medicina Paliativa, but there are still too few graduates to meet demand (there were an estimated 30 or so professionals with this specialty as of 2012). Despite local initiatives, palliative care is still not recognized as part of health services (Palmeira, Scorsolini-Comin and Sanches Peres, 2011), which is why the federal government needs to establish a national health policy to consolidate palliative care in Brazil.

Argentina, Chile, Costa Rica and Uruguay were classified by WHO at the most advanced levels for the region (but not the world). Although there is more awareness of the importance of palliative care and more professionals and services have become available in some of these countries, there has not as yet been any real policy consolidation.

In Argentina, palliative care services were first provided by isolated private centres in 1982, before eventually being incorporated into frameworks of health-care regulation in 2000.

Current legislation in Argentina includes the right to comprehensive palliative care as part of treatment, this being enshrined in Law 26742 on patients’ rights.\(^10\) However, this law has not been adequate, since the country’s administrative code grants each province the autonomy to set its own standards and some have not incorporated palliative care services. In fact, just 10 of the 24 provinces have legislated for palliative care.

In addition to this law, commissions and programmes have been set up within the Ministry of Health and the National Cancer Institute. These initiatives are not backed up by earmarked funds or by oversight and monitoring mechanisms, and thus have been unable to universalize palliative care services.

There are at least five research centres dealing with the issue in Argentina: Pallium Latinoamérica, the Foundation of the Medical Federation of the Province of Buenos Aires (FEMEBA) Tornú Hospital, the Palliative Care Department of Udaondo Hospital, the Alfredo Lanari Medical Research Institute of the

\(^9\) In Honduras, a bill was presented in 2014 on palliative care for patients with terminal chronic illnesses, dealing with access to opioid medications for patients in the terminal phase or with chronic diseases and giving these the right to decide when to suspend medical treatment and obtain assistance to die.

In Chile, regulations do include palliative care, and all health-care providers in the public and private sectors are required to provide palliative care services to advanced-stage cancer patients. The National Programme of Pain Relief for Cancer and Palliative Care was set up in 1994 with the support of the Ministry of Health (MINSAL, 1999). Nine years later, in April 2003, this Programme was incorporated into the System of Universal Access with Explicit Guarantees (AUGE), a health-care improvement and affordability programme (MINSAL, 2006).

In Costa Rica, palliative care is covered by the universal social security scheme. Hospitalization, medication and specialist consultations are provided free of charge, and there are NGOs that support the uninsured.

From the legal point of view, although Costa Rica has not legislated for palliative care, the Constitutional Chamber has issued resolutions relating to the rights of terminally ill patients. One of the first and most significant was a 1994 ruling enshrining the right to a dignified and pain-free death.

The issue was institutionalized in 2008 with the creation of the National Council for Palliative Care, comprising representatives from the Ministry of Health, the Costa Rican Social Security Fund (CCSS), the National Centre for Pain Control and Palliative Care, the Costa Rican Palliative Care Federation, the Social Protection Committee (JPS) and some foundations.

Trinidad and Tobago is gradually introducing a palliative care framework. There are several centres that provide care for terminal cancer patients, and in 2014 the first government-funded palliative care hospital unit was opened, but this is still not enough to meet demand. The availability of pain control medications also continues to pose a problem. The University of the West Indies launched an MSc in palliative care medicine in 2012.

The situation in Barbados is slightly different. Opioids and other essential medications are generally available, although the country still lacks a specialized palliative care structure. The Ministry of Health and NGOs have been working to improve end-of-life care services. The Barbados Association of Palliative Care, an NGO founded in 2011, provides support and care for the terminally ill. The Barbados Palliative Care Needs Assessment, commissioned by the Ministry of Health, reported in 2012 that a palliative care centre was needed. Plans are now afoot to build one, to be operated by the Barbados Cancer Association (BACA) along with another NGO.

In the WHO ranking, all the region’s countries came below the United States, the United Kingdom, Australia, Sweden and Japan, among others. They do meet a number of the requirements for consolidating palliative care in the region (research, professional training, availability of medications, subsidies to reduce out-of-pocket spending, progressive public spending on palliative care and broad awareness of its contribution and the need for it, among other things).

Cuba is one of the countries in the region that stands out in this area. The Pain Management and Palliative Care Programme (PADCP) for cancer patients is part of the free universal national health system. The PADCP includes home care by multidisciplinary teams of doctors, nurses and psychologists. It also covers free hospitalization and medication during treatment. The Ministry of Health has made a proposal
to include the palliative care component in primary health care as part of the Family Doctor and Nurse Programme in the interests of ensuring long-term management of disease and helping people cope with bereavement. The overall objective is to enhance the subjective well-being and quality of life of cancer patients requiring palliative care and their families by providing comprehensive care that encompasses physical, social, emotional and spiritual needs, while avoiding ill effects for the medical team. Palliative care training, meanwhile, has been officially accredited since 2010 in the form of a diploma in palliative care for adult patients and a national diploma in cancer management. Faculties of medicine also include palliative care content.

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